

**Exploring Mechanisms for Public Engagement**  
*Joan A. Scott, M.S., CGC*

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MS. BERRY: Let's get started. We will dispense with the chart, the Reed Tuckson chart, but I will highlight just a few key points, and that is some folks have mentioned the coverage and reimbursement report that we worked on at the last meeting. That is being finalized. Staff had some additional editing recommendations. We anticipate having final activity on that and get the report out in short order. For members of the committee, there were some editorial recommendations. We'll get copies of those in redline tonight. I ask that everybody take a look at those, and tomorrow we will either go yea or nay. So we will either go back to the original version that we proposed or we will accept the staff recommendations for the editing changes, and we'll move the coverage and reimbursement report forward.

Another item I wanted to call to everyone's attention is the fact that the committee deferred consideration of the issue of gene patenting until the National Academy's Committee on Intellectual Property Rights in Genomic and Protein-Related Inventions issues its report. That report is due out next month, November 9, and given its imminent release it might make sense for us to task a small group to review the report and provide us with some input about its recommendations and findings and whether there are issues this committee should take a look at.

I think, Debra, am I correct in assuming that you will graciously agree to head up a little working group for that purpose?

DR. LEONARD: Sure.

MS. BERRY: So anyone interested in volunteering to work with Dr. Leonard on the little, small work group and analyzing that report, see Debra, and that will move forward.

Another clean-up item. I wanted to draw to your attention a survey that's in the table folder. HHS would like feedback from members and ex officios about the effectiveness of the committee's activities. So we'd ask that you complete that survey and hand it to Abbe Smith at the registration desk before we adjourn.

Finally, I will turn everything over to Sarah Carr, who is going to give us kind of an update on what we should already know and be acting upon with regard to ethics rules.

MS. CARR: Right, and in the interest of time, I'm not going to go through my usual reminders, because I know you all are very attentive to the conflict of interest rules. So I won't go through that, but because we're also going to hear about legislation tomorrow, you want to remember that you can't lobby while you're here.

I also want to just mention that in June I also sort of lectured you about the Emoluments Clause, and there's been a development since June. The Justice Department has issued a ruling that the Emoluments Clause will not apply or does not apply to certain special government employees. It's not across the board. It sort of depends on the nature of the committee that the SGE is serving on, but an analysis has been done of our committee, and the members of our committee are not subject to the Emoluments Clause unless you are on another committee. So if you're on another federal advisory committee, then don't assume you're not covered for that committee. We'll be getting you more information about this as the implementation of this change, significant change, is carried out. But I did want to mention it because I had brought it up in June and because I know a number of you from time to time think about doing some work overseas.

Then the last thing I'll say is that there's still a form that you will probably have to fill out about this, so you're not totally off the hook. But anyway, thank you.

DR. WILLARD: Welcome back. We'll continue with our session on large population studies, and specifically now we're going to hear from four experts in the area of public engagement who will together make up a panel, who are waiting patiently at the head of the table. I think, from an organizational standpoint, we will not have questions following each presentation. So, committee members, if you can take notes and save them up, and then we'll have a panel discussion when all four speakers have completed their presentations.

So first we'll hear from Joan Scott. Joan is a certified genetic counselor with over 25 years of experience in clinical genetics, the biotech industry, and in genetic policy, and she's now the deputy director at the Genetics and Public Policy Center of Johns Hopkins University.

Joan, thank you for joining us.

MS. SCOTT: Thank you for the invitation. I elected to come up here so I could drive, not that I have a control issue or anything.

(Laughter.)

MS. SCOTT: So I appreciate the opportunity of coming to talk with you today about public engagement, to engage on this subject. I have divided my time into three areas. First of all, I'd like to spend just a couple of minutes talking about some general principles about public engagement, because we hear that term used a lot, and it can mean a lot of different things to a lot of different people, and there are many different levels at which you can engage the public. So I think to help inform our discussion later on, it would be useful to take a few minutes just to talk about what the universe of public engagement is. Then I'll talk about our experience with the genetic town halls and how information that we learn might inform a public engagement activity around large population studies; and then specifically the committee had some questions that they wanted me to address, and I'll close with those.

So first of all, just from a very basic perspective, what do we mean about public engagement? You can, as I say, engage the public at a lot of different levels. At the very simplest end of the spectrum, you can simply want to inform or educate the public, and we heard this morning that that's a necessary thing to do. Some would argue as to whether or not that's really public engagement because you're not requiring much work on the part of your participants, except passive receptivity to the information. But nonetheless, in your overall strategy, that is one method where at times it will be an important component of your overall strategy.

It does, however, sort of imply that you've got a one-way communication going on, whereas a more consultative approach to public engagement assumes that the public brings to the issue and the topic some very valuable experiences and perspectives and values that will help inform your overall policy issue or whatever it is that you're consulting them about.

That said, however, again there are a lot of different levels at which you can engage the public. Doing surveys can help inform what the public thinks, knows and feels about a particular topic. Doing focus groups, moderated focus groups, will give you a little more nuanced understanding about what the public's attitudes about issues are and some of the values that shape those opinions. You can ask the public to do a little more work in looking at the issues through

workshops or scenario development. In deliberative democracy, you provide an opportunity for your participants to learn more about the subject, hear from the experts, hear the different points of views discussed and debated, and then to deliberate about those issues. Then ultimately, you can ask them to do the ultimate work in actually coming to a consensus agreement about what the best policy option is.

So there's lots of different levels at which to engage the public. The one thing that's common about these particular approaches that I've discussed is that the issues identification and agenda-setting tends to rest within the hands of the organizers, whereas a more collaborative approach to public engagement invites the community, however you want to define that community that you're engaging, early on in the process in the issues identification, framing the issue, prioritizing what the issues are for that particular community, helping set the agenda for what those engagements are actually going to look like, helping devise outreach strategies within that engagement.

The farthest end of the spectrum can not only empower your participants to make the decision, you can agree to abide by the decision that they arrive at. Now, I suspect that's not going to be the method that will be chosen here, but you can do that.

So with that as a background, as I say, there's lots of different ways of engaging the public. So when you hear that term, it can mean a lot of different things depending on what your ultimate goals are for the engagement, where you are in the development, in the maturation of that particular issue, and how far along the public has come in the evolution of their thinking about that particular issue, and very importantly, who you are engaging. So in the case of a large population study, for example, are you aiming your engagement to the communities from which you want to recruit participants, or are you looking at a more national or regional conversation about these issues at large? Very different communities there and different approaches that you're going to want to use.

So with that sort of as a background about the whole universe of ways to engage, let me talk about what we did and why we did it the way we did it and our experience with the genetic town halls, which we held in six cities around the United States during the summer of 2004, and over the same time frame we held 15 discussion groups online.

Now, the topic that we were specifically engaging people about was reproductive genetic technologies, and we had already done a great deal of background work around what the public thinks, knows and feels about these issues in the way of several surveys, focus groups, interviews, et cetera. So we did not use the more collaborative approach where you go into the community and ask them to help identify the issues important for them, because we already pretty much knew what the issues were and what different populations were saying, and why.

But one of the criticisms of this approach in getting feedback from the public is that you're sometimes asking people to comment about technologies or issues about which they may have little personal experience or have had little time to reflect on in depth. So a deliberative approach to obtaining information back from the population sets a stage where you provide your participants, as I said before, with more in-depth background information about the topic at hand, what the issues are. They have an opportunity to hear experts debate about the various perspectives, and then have an opportunity to deliberate with the experts and with their fellow participants about these issues.

To have a credible deliberative process really requires four things be in place. First of all, the participation must be broad and representative, and I'm speaking of that from two perspectives. First of all is your initial outreach into the community. Everybody should have the opportunity, should be aware of the engagement and should have the opportunity of participating. Within the engagement process itself, all voices should be there in the room, so that the people who are participating have an opportunity to hear what the range of perspectives are to help inform their own opinion-making.

The information that's presented should be balanced and accurate and fair, and then the environment needs to be such that there is a safe and ample opportunity for everyone to hear and to be heard. The fourth point we think is equally as important, that the policymakers, the decision makers are part of this process from the beginning. If you're going to ask people to take their very valuable time to think about these things and deliberate about them, they should know that there's going to be an impact from the time that they're spending.

So this is what we did. In order to ensure that the content was the same and balanced and fair in all of the locations where we held the town hall, rather than fly our expert panel around the country with us, as much as we would have loved to have done that -- it would have been a lot of fun -- we packaged them. We carried them around on a little DVD. So the town hall report that you have in the back of that is the DVD that's got those four videos.

The first one was an animated overview of what reproductive genetic testing is, and the next three we interviewed and edited together comments from experts conveying various perspectives on the three issues that were the topic of those town halls.

We partnered with a group in D.C. called the Public Forum Institute, and the recruitment for the town halls was through local coordinators who knew their communities, and they used a variety of outreach strategies, including putting notices in high traffic areas such as libraries, hospitals, clinics, grocery stores, community centers, as well as more targeted outreach to community organizations and leaders.

We also did a media push in each of the locations that we were going by placing op eds, working with local reporters, talking on local radio talk shows, placing ads in the newspapers, et cetera.

So we asked people to register ahead of time so we could monitor our recruitment. When people came to the town halls, this is what it looked like in a couple of the sessions. They were able to sit at these round tables of about eight to ten individuals. We started the session by obtaining some background demographic information on knowledge and attitudes around these issues. So we asked 36 questions up front, eight of which we repeated at the end of the session to see if there was a shift in attitudes.

The town halls were about three and a half hours long, and they varied between presenting some of the content and then the participants taking part in small and large group discussions.

All of the participants were given these hand-held electronic devices so that we could collect the data electronically, but also periodically throughout the sessions we asked groups to call out, if you will, things that were of concern to them. I don't have a pointer, but those would get entered into the computer there and then shown up at the front of the room to help inform the large group discussion, and people could vote and then rank order on those issues.

The last half hour, then, was always a community panel of community leaders from a variety of different perspectives.

The online group, as opposed to meeting for one three-and-a-half-hour session, met for three one-hour sessions over the course of three weeks, and this was recruited through Knowledge Networks' web-enabled panel, which was representative of the general population. These are over 40,000 households that have been recruited by Knowledge Networks through random digit dialing, and if the household did not have Internet access, they were given Internet access to help get over that sort of divide there.

Because we were doing this online, for that group of people who agreed to participate in the discussion groups, we could do more data collection. So they took an 80-item survey up front, and then selected the time slot -- we had 15 different time slots they could choose from -- and mailed them all of the headsets and instructions ahead of time, and those sessions were moderated by genetic counselors. This is what it looked like on the screen to them without all of the little boxes there. But on the side was a list of the names of who was participating in their groups, and we kept the groups together over the course of three weeks. So John and Sally and Mike all got to know each other pretty well over the course of those three weeks. Then participants could request the microphone and then speak in turn.

The majority of the engagement was through audio, but on the side was a box to do text messaging, and usually we had actually two conversations going on at the same time. For those of us who have a hard time walking and chewing gum at the same time, you had the audio going on and then you had the text messaging going on.

Then about a week following the last session, 76 of those questions were repeated again to document changes in knowledge and attitude.

Another one of the advantages of doing some of this online is that you could run a control group, and we had 400 individuals matched to the participants that took the pre-test and the post-test but did not participate in the discussions in between.

So we collected a lot of data on these individuals, and I'm just going to highlight three important things. One is who participated, because it was slightly different in the two groups. We had 133 that we ended up counting as full participants in the online. So they had to have taken two of the three sessions and done the pre- and the post-test, and they were fairly representative, although a small number, of the general population.

The in-person participants differed significantly in three areas. First of all, they were more highly educated. So they were more likely to have had a college degree or higher than the participants in the online group. The religious distribution was different. The in-person participants were less likely to say that they were Protestant but more likely to say they either had no religious background or self-identified as Evangelical or fundamentalist. The third major difference is that the in-person participants were twice as likely to either have had a genetic test or someone in their family had a genetic test.

So the point is that people who take three and a half hours out of their very busy schedules to come to an engagement around this are more likely to be stakeholders and they're more likely to come with a particular background or perspective.

The second point about what we document is that we did document shifts in opinion before and after, and I'm only going to show you one data point. This is from the online group. We asked individuals whether or not they approved of the use of PGD or prenatal diagnosis for things such as fatal childhood disease, down to a more hypothetical testing for traits such as intelligence or strength, and this compares the online group with their controls. You can see that the online group started off a little more approving, but they both followed sort of that same general decreasing level of approval for the use of these technologies.

What's significant, though, is at the end of the engagement process, the control groups -- so time 1 is solid and time 2 is hatched -- the control group did not shift in their opinions over that month to six weeks. The way they thought at the beginning was the same way at the end. The participants in the discussion group, however, with the exception of the testing for fatal childhood disease, there was a significant dropoff in approval for all of the other technologies.

So the moral of the story is that engaging the public does not necessarily make them approve of what you're doing, and that's an important point.

The last point I want to make as far as some data that we collected, the topic was reproductive genetic testing, but the conversations really ranged from all areas of advances in genetics and people's optimism and concern around those issues. We kept hearing several themes come up repeatedly. One was people's concerns about the use of genetic testing, and I believe Kathy Hudson has presented before this group previously about some of our findings there. We also heard a great deal of concern about all segments of the population having access to benefits of advances in genetics.

So both of the methods did allow for nuanced, reflective conversations around these technologies. There are some advantages and disadvantages to both the online group, which by its very nature allows you to collect more data, and it's possible to track that information over time. On the other hand, the in-person town halls had a wider ripple effect because we were involving community leaders and there was media involvement. There was a wider ripple effect in that particular community.

So how does that inform having a public engagement in a large population study? Well, first of all, again, you're going to be talking to different segments of the population at different points in time, and so there's going to have to be different methodologies that are appropriate for your entire engagement strategy. The methods that we used are very exportable, and they're also expandable. Our six town halls were held independently of each other. There's no reason why -- and this actually has been done -- you can't link up the town halls and have all six of them going on at the same time, devote part of your program to a national conversation and part of the program to local issues.

Televising town halls and having increased media involvement would also have a wider benefit in reaching a wider audience and having this broader ripple effect. I do think that tracking over time is important so you can monitor what the effect is that you're having in a particular population. That's very doable using Web resources or to use that as a tool to have supportive information for the community and participants.

We were asked specifically to address whether or not in our experience of engaging the public we felt that the public would be receptive to a large population study, and I have to say that's not a question that we asked, and that would be a reason for doing a public engagement activity, to find out that very issue.

I will say again that in general, we found that people were very optimistic about advances in genetics and the potential health benefits for those advances in genetics. Where they become concerned is where the rubber hits the road, so to speak, ensuring that everybody has equal access to those and that the information is not being used to discriminate.

Some challenges are always, of course, ensuring broad and representative representation, and that's always difficult. So engaging the community, however you want to define that, early in the process and having them part of the decisionmaking and agenda-setting is very important. The other major difference of what we were doing is we came into a community once. We were not having an ongoing and repeated conversation with that community, and that's a big difference between what we do and what some other efforts have been.

The last thing I mentioned here under barriers is the credibility issue. People look as to who is sponsoring an engagement activity because they're expecting that there is going to be a point of view and a perspective, even if it's subtle, that they're going to try to be persuaded about something. I have to say that one of the most gratifying comments that I got was after our very last town hall. A participant came up to me and she said, you know, we always hear that these things are going to be balanced and fair and everybody has an equal voice, but it's usually not the case. You get there, and even if it's subtle, there's a point of view. And she said, I have to say, I came here and there was not a perspective, and all voices really were heard. That was very gratifying to me because we had spent a great deal of effort to make that so, but it does require effort to have that sort of credible balance.

So I think with that I will stop, thank our funders who helped support this project as well as others, and turn it over to the next speaker. Thank you.

DR. WILLARD: Thank you, Joan, very much for that.